

UNIVERSITÄT BERN

Interdisciplinary Centre for Gender Studies

# Women with disabilities in Nepal

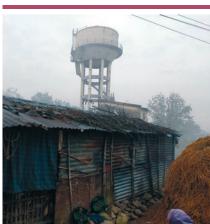
Photovoice study on the barriers and enablers to social, economic and political inclusion













#### **EXECUTIVE SUMMARY**

This exploratory study focuses on the lived experiences of women with disabilities in Nepal and their social, economic, and political inclusion. Currently, existing data and statistics on persons with disabilities in Nepal are extremely scarce, confusing, and even contradictory. The present qualitative study aims to be a modest scientific contribution to this field. The overall purpose of the study is to identify barriers and enablers to access to social, economic and political life for women with disabilities, especially for women from marginalized groups. This study was carried out in accordance with feminist principles of research using the Photovoice method. In-depth interviews were conducted with ten women with disabilities based on the photographs they took. Intersectional theory and the social inclusion framework constitute the theoretical background of this study.

The results show that women with disabilities face multiple instances of discrimination and stigmatization, yet the main discriminatory factor is the disability itself. Furthermore, gender intersects with disability, as well as with other social categories – such as belonging to a marginalized ethnic group (e.g., an indigenous community) or to a marginalized caste or speaking a minority or indigenous language. Stigmatization and discrimination are exacerbated by the intersection of the different social categories. Moreover, multiple discrimination and stigmatization are visible at all levels – household, community, and national levels – and throughout the life of a woman with a disability. This leads to the

marginalization of women with disabilities in the Nepali society and renders them more vulnerable to gender-based violence. Additionally, lack of accessibility (in terms of transportation, roads, buildings, health care and health professionals), disability related extra costs, and lack of self-confidence are other underlying factors that hinder the full inclusion of women with disabilities.

Enablers for a successful economic inclusion are skill training in combination with financial support, access to information and a supportive community and environment. Successful economic inclusion, peer support groups and mobile phones have a positive impact on their social participation. Furthermore, organizations of persons with disabilities play a major role in the lives of women with disabilities. On the contrary, the results indicate a strong dissatisfaction with the performance of the Nepali government as guarantor of their wellbeing and rights, suggesting a secondary role in the lives of women with disabilities. Along the same lines, their interest in politics is very low, which goes hand in hand with a high level of distrust and low expectations of politicians and the political system. In conclusion, the results of this study show that multiple discrimination and stigmatization at all levels and throughout life are the main barriers to the social, economic, and political inclusion of women with disabilities, subjecting them to precarious living conditions and placing them on the margins of society.

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This study was conducted by the Interdisciplinary Centre on Gender Studies (ICFG) at the University of Bern. The ICFG works as a competence center for inter- and transdisciplinary gender research at the interface between academia and practice. It regularly takes on mandates and advisory duties in relation to socio-politically relevant issues from a gender point of view.

The study was accompanied by a steering group consisting of the Swiss Disability and Development Consortium (SDDC) partners in Switzerland and Nepal, as well as four partner organizations of persons with disabilities (OPDs) in Nepal. The SDDC is a network advocating for the rights and inclusion of persons with disabilities in Swiss international cooperation. It was founded in 2016 and its members include CBM Switzerland, FAIRMED, Handicap International Switzerland, and the International Disability Alliance (IDA). For this project, SDDC member counterparts in Nepal were engaged throughout the process.

The Nepali OPDs engaged in this study include the Nepal Disabled Women Association (NDWA), the National Indigenous Disabled Women Association Nepal (NIDWAN), the Blind Women Association Nepal (BWAN) and KOSHISH.

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"If there were proper infrastructure, then no one will feel like they are disabled."

Accessibility of infrastructure



"This is my livelihood, what can I do? This is what fills my stomach."

Source of livelihood

# 1 INTRODUCTION

CBM Switzerland, in collaboration with the Swiss Disability and Development Consortium (SDDC) mandated the Interdisciplinary Centre for Gender Studies (ICFG) of the University of Bern, Switzerland, to conduct an exploratory Photovoice study in Nepal, focusing on women with disabilities.

Research-based data on women with disabilities in Nepal are very scarce and sometimes inconsistent (Poudyal et al. 2018; USAID 2017; Eide et al. 2016). The present exploratory study aims to be a modest scientific contribution to this field, with the objective of beginning to fill the existing research gaps, particularly around the social, economic, and political participation and inclusion of women with disabilities in Nepal. The overall topic of the study is to identify barriers, discriminations, and enablers of access to social, economic, and political life for women with disabilities, with specific attention to women with disabilities from marginalized groups. Taking into account that different thematic areas overlap (e.g., access to employment, education and vocational training, health services, social protection) and that women with disabilities face multiple discrimination, an intersectional approach was applied. As the study was carried out with a participatory/transdisciplinary approach, local partner organizations and participants were involved during the research process.

Based on the overall topic the following leading research question was formulated:

What are the barriers to and enablers for the social, economic, and political inclusion of women with disabilities in Nepal?

The qualitative study gives insight into the lives of women with disabilities in Nepal and outlines important factors of exclusion and inclusion of women with disabilities regarding their social, economic, and political lives. The study also includes recommendations for different stakeholders. Since this study was conducted using the Photovoice method, the research participants were encouraged to take pictures of their daily lives. These pictures were the starting point for the qualitative in-depth interviews, and a selection of them can be found throughout the study.

#### THE PURPOSE OF THE STUDY IS:

To identify from women's lived experience the barriers and enablers to social, economic, and political inclusion

To have evidence-based results for recommendations regarding the social, economic, and political inclusion of women with disabilities in Nepal

# 2 STUDY CONTEXT - NEPAL

Nepal is a landlocked and mountainous country with both highland and lowland areas. Agriculture is the backbone of the economy and the main source of livelihood for over 70 percent of the population (The World Bank 2018). Nepal's labour market is divided into formal and informal sectors. While the formal sector is provided with benefits such as formalized paid leave and social security, which are guided by labour market regulations, the informal sector lacks such benefits. As the Nepal Labour Market Profile points out, more than 70 percent of the economically active population is engaged in the informal economy (DTDA 2019). Women in the informal sector face various safety and health risks, gender-based violence, and dangerous working conditions (Gosh 2021). Despite being part of the paid labour market, women in Nepal shoulder the overwhelming share of childcare and domestic work (UN Women 2015). Compared to other countries worldwide, Nepal does not perform well on gender equality. According to the World Economic Forum (2019), which compiles the "Global Gender Gap Index", Nepal ranks 101 out of 153 countries. The index indicates the relative disadvantage of women, which is classified into four categories: economic participation, political empowerment, education, and health (World Economic Forum 2019).

In Nepal, the existence of patriarchal structures and practices has resulted in many rights not being guaranteed equally to women and men. In recent decades, several laws and policies have begun to emphasize women's rights and gender inclusiveness in various aspects. In particular, the country's sixth five-year plan

(1980-1985) incorporated women in development policy by creating a separate section to recognize women's role in development, gender equality and participation in various sectors (Sijapati 2021). The promulgation of a new constitutional arrangement in 1990 also stands as a major milestone in advancing gender equality. However, women were not part of the drafting of the constitution and had less representation (Malagodi 2018). Also, between 1990 and 2015 and particularly with the redrafting of the constitution in 2015, the Supreme Court has made women's rights in Nepal more progressive, providing more rights to women (such as the right to own property), implementing quota systems in different areas (for example to ensure equal access to jobs and leadership positions in political parties), and prioritizing the protection of women and marginalized communities (ADB 2016).

Although the caste system in Nepal was abolished in the 1960s, the practice is still widespread and pervasive. The upper caste categories (Brahmins, Chhetris) dominate the lower castes (Vaisya and Sudras). The most vulnerable are the Sudras or those labelled as Dalits, who represent about 15 percent of the country's population. Nepal is home to a unique and rich culture, compiling diverse beliefs and multiple languages. The census of 2011, which is the most recent, records 125 (sub)-castes and 123 languages spoken across the country (Limbu 2015).

#### 2.1. PERSONS WITH DISABILITIES IN NEPAL

Obtaining reliable and quality data on disability and its current prevalence levels remains a challenge: the collection of such data faces several difficulties such as the adoption of various conceptual frameworks reflecting the constant changes in the definition and classification of disability or methodological discrepancies in screening processes (Eide et al. 2016; Holmes et al. 2018; Poudyal et al. 2018).

While some national studies and surveys have been carried out, the figures obtained are considered to be unrepresentative and an underestimate of the actual figures (Eide et al. 2016; Holmes et al. 2018; Poudyal et al. 2018). While the latest national census conducted by the Government of Nepal in 2011 reported that 1.94 percent of the population has some form of disability, the National Living Standards Survey Report estimates that figure to be 3.6 percent (Eide et al. 2016; Holmes et al. 2018). However, there are arguments that the estimated prevalence of disability in Nepal is underreported due to existing societal taboos. Specifically, persons are thought to be born with disabilities due to family curses and sins committed by family members (Karki, Rushton, Bhattarai and Witte, 2021). Due to these beliefs, many households do not report that members have disabilities to keep them hidden or persons with disabilities do not disclose their disabilities in certificates (Karki, Rushton, Bhattarai and Witte, 2021). The WHO World Report 2011 considers that around 15 percent of the world population are persons with disabilities (WHO 2011). Moreover, most of the available data for Nepal are not disaggregated by sex, socio-economic status or caste/ ethnicity (USAID 2017), which is an impediment to analysing the multiple disadvantages and discrimination to which persons with disabilities, especially women are exposed.

Despite the existence of multiple constitutional, legislative and policy instruments at the institutional level in Nepal aimed at protecting and promoting the rights of persons with disabilities, there are huge implementation gaps. These gaps result in substantial barriers to full participation in the economic, political and social spheres, particularly for women with disabilities (NDWA 2019a). The situation for those with disabilities and coming from marginalised communities is worse, as they face dual ostracization. Moreover, the situation for minority women with disabilities is even poorer (Timilsina, 2018). The difficulty of effectively implementing the commitments made is due to several factors, including lack of adequate data and information, limited institutional capacity, low levels of rights-based awareness, lack of legal and political support and entrenched and overlapping discriminatory practices (NDWA 2019b; USAID 2017).

# 3 DEFINITIONS AND THEORETICAL APPROACH

The terms and definitions used throughout this study are in accordance with the UN Convention on the Rights of Persons with Disabilities (CRPD). Intersectional theory and the social inclusion framework constitute the theoretical background of this study.

# 3.1. UN CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The CRPD states that: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others." Disability, then, is distinct from the impairment itself: disability arises from the interaction of impairments with institutional, attitudinal, environmental, and communicational barriers that limit a person's equal participation in society (United Nations 2006; WHO & World Bank 2011). This definition frames disability as a social rather than an individual problem that can be addressed by removing the barriers that create emotional, social, political, and economic inequities for persons with disabilities (PDWA 2019). Furthermore, the General Obligations of the CRPD (Article 4) stipulate the involvement of OPDs for the development of legislation and policies to implement the Convention (United Nations 2006).

Already in 1982 Nepal put into force the Disabled Persons Protection and Welfare Act to address the concerns of person with disabilities (Timilsina 2018). The CRPD ratified by Nepal in 2010, also recognizes that women with disabilities are subject to multiple discrimination and that their full development and empowerment

must be ensured for them to enjoy their human rights and fundamental freedoms (United Nations 2006). Under the federal system of government, the Constitution of Nepal, has provided space to address the needs of persons with disabilities through the enactment of the National Act for Persons with Disability 2017 (Adhikari 2019). This Act has detailed aims, policy measures, and plans of action to ensure health, education, livelihood, skill development and employment rights for persons with disabilities.

However, denial of rights, unequal access to basic services and opportunities and stigmatising, exclusionary and discriminatory practices against persons with disabilities – and especially against women with disabilities – continue to be commonplace (Dhungana 2006). Moreover, these practices ingrained in society create substantial barriers that negatively affect the well-being of women with disabilities who are often denied access to health, education, employment or social services; are limited in their participation in social, cultural and political spaces; and are exposed to higher rates of abuse and violence (MacDonald et al. 2021).

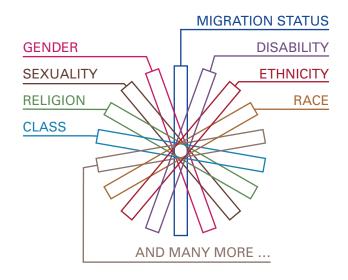
In 2018, the Committee on the Rights of Persons with Disabilities noted in its "Concluding Observations on Nepal's Initial Report" that the State party should strive to "implement existing legislation, policies and programs on discrimination in order to prevent multiple and intersectional discrimination against disadvantaged groups, including autistic persons and ethnic, Dalit, Madhesi and Muslim communities" (United Nations 2018: 2) and to "protect all persons with disabilities from exploitation, violence and abuse both within and outside

home" (United Nations 2018: 5). Furthermore, the Committee on the Rights of Persons with Disabilities recommended developing and implementing awareness-raising education programs and "ensur[ing] that persons with disabilities throughout its territory have access to community-based rehabilitations services and adequate social protection programmes that are oriented towards social and community in-

clusion" (United Nations 2018: 7). Additionally, the Committee on the Rights of Persons with Disabilities focused on women with disabilities and pointed out that the State party should ensure their participation in the political and public life and should prevent and combat all forms of violence, including sexual violence (United Nations 2018).

#### 3.2. THEORY OF INTERSECTIONALITY

Historically, feminist theories have sought to draw attention to the intertwining of power relations and the overlapping of different forms of discrimination. Kimberlé Crenshaw (1989) coined the concept of intersectionality to shed light on the multiple dimensions of oppression experienced by women. Through this concept, Crenshaw emphasized that women are exposed to numerous forms of violence and discrimination not only on the basis of gender, but also on the basis of several other socially constructed categories such as class, race, ethnicity, religion or disability - to name but a few. Intersectionality is thus constituted as an analytical perspective that reveals the ways in which multiple forms of inequality overlap or intersect. In other words, intersectionality is a lens for understanding and analysing the complexity in the world and in persons experiences (Hill Collins and Bilge 2016), a concept for thinking about how different criteria of discrimination interact. Adopting this perspective for the research process implies recognising the heterogeneity of women's experiences. It allows to go beyond linear single-category thinking and to understand the ways in which multiple socially constructed categories often operate



Theory of Intersectionality (Pita 2021)

simultaneously and exacerbate each other (Carastathis 2016; Hill Collins and Bilge 2016), with highly tangible consequences for the lives of women with disabilities.

In this study, intersectionality as an analytical tool allows us to focus on the ways in which gender intersects with disability – as well as with other categories (e.g., indigenous group, ethic minority, cast) – and the impact of this operation in terms of the discrimination, stigmatization and exclusion of women with disabilities in Nepal, whose perspectives, lived experiences and knowledge constitute the centre of this research.

# 3.3. THEORETICAL BACKGROUND OF SOCIAL-ECONOMIC AND POLITICAL INCLUSION

Considering the pervasive nature of exclusion experienced by women with disabilities, this study analyses the exclusion/inclusion dyad using the social inclusion framework proposed by Welsby and Horsfall, published by the World Bank (2013). Social inclusion is intrinsically linked to human well-being and social justice. It refers to the process of improving the conditions for individuals and groups - which are disadvantaged based on their identity - to take part in society and to increase shared prosperity. This approach starts from the consideration that individuals and groups participate in society through three interrelated domains: markets (land, housing, labour and credit), services (social protection, information, transportation, education, health and water) and spaces (political, physical, cultural and social).

Each of these domains represents not only barriers to but also opportunities for social inclusion. Given that markets, services and spaces are highly interconnected, efforts to reduce the exclusion of women with disabilities cannot be limited to intervention in a single domain. Social exclusion is a multidimensional process in which certain practices in one domain lead to or reinforce exclusion in another domain. Consequently, interventions – be they state or non-state driven – whose overarching goal is to improve conditions of access and participation must be designed with this consideration in mind (World Bank 2013).

### **4** STUDY DESIGN AND METHODOLOGY

As mentioned in the previous section, research efforts on disability in Nepal are incipient and research-based data remain scarce. The present exploratory study was carried out according to feminist principles of research. This approach allows for discussion and reflection on the power relations and imbalances between researchers and research participants, but also within the research. The core principles of the study are as follows: addressing power relations, broadening the questions asked, listening to women's voices and experiences, incorporating diversity and intersectionality, conducting multidisciplinary and mixed-methods research, reflecting on one's own position and the whole research process, establishing social relationships in the research process as well as discussing and sharing the research results with all stakeholders and with policy makers (Westmarland and Bows 2019). The research team took into consideration the following additional

ethical issues: all data and information will be kept confidential at all times with assurance provided to respondents in advance. Moreover, informed consent was obtained from all participants for the conduction of this study.

From the conceptualization of this study through to its publication, the formation of a steering group was key to ensuring accountability and ownership. The SDDC members in Nepal and Switzerland provided overall strategic direction and guidance throughout the process. The SDDC also identified four OPD partners in Nepal (NDWA, NIDWAN, BWAN and KOSHISH), who in turn selected and coordinated with the ten participants. The OPD partners and SDDC members also played an active role in reviewing the study and the recommendations.

#### 4.1. PHOTOVOICE

Considering the centrality of lived experience in feminist research, qualitative data collection in this study was carried out using the Photovoice method. This participatory arts-based research method, developed by Caroline Wang and Mary Ann Burris, uses the "immediacy of the visual image to furnish evidence and promote an effective, participatory means of sharing expertise and knowledge" (Wang and Burris 1997). Photovoice brings together both feminist theory and critical consciousness and is seen as a tool for effecting social change and for reaching out to policy makers and key stakeholders (Christensen 2017). This method follows the principles of transdisciplinary research (Godden

et al. 2020; Pohl and Hirsch Hadorn 2007) by placing research participants in the spotlight, who are invited to take photographs of their everyday lives and to use these images to tell stories about what they consider important (Wang und Burris 1997). By encouraging participants to talk about the issues that are relevant to them, Photovoice provides the opportunity to see the world through the eyes of the individual and allows outsiders to gain insights into local realities and vulnerabilities (Duffy 2018). In this way, some power can be shifted from the researchers to the participants (Ascroft 2020), who are included in the process as co-researchers and as experts of their own experiences.

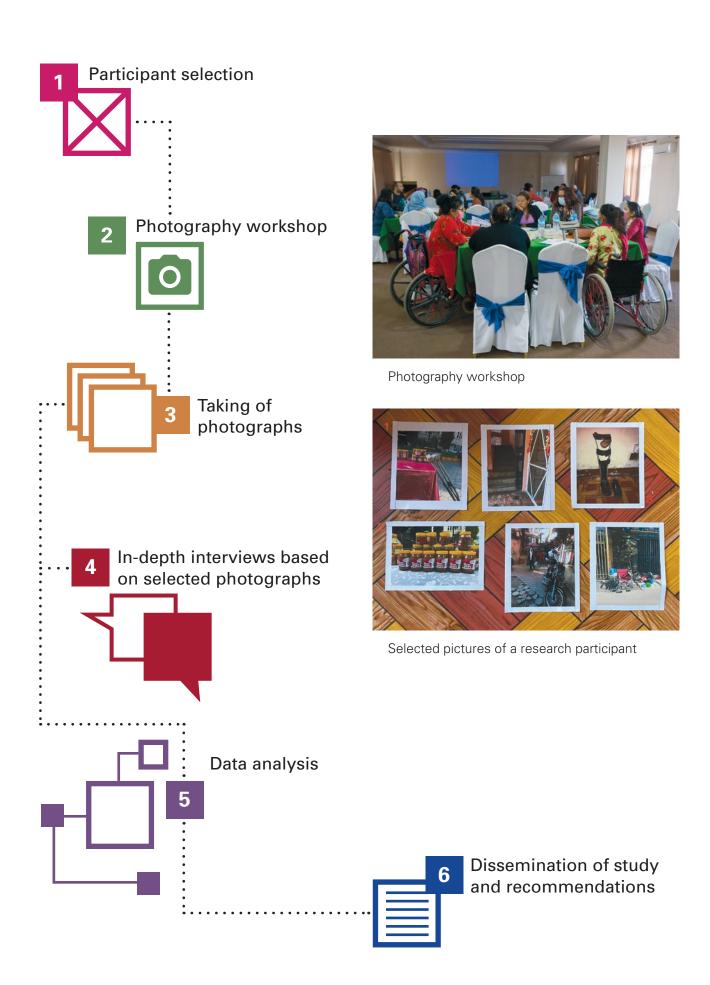
Since its inception, the Photovoice method has been widely used in qualitative research and has been employed to investigate issues relevant to women and particularly those topics that arise at the intersections of gender and other social categories (Delaney and Macdonald 2018). In this sense, this method proved to be appropriate for exploring the experiences of women with disabilities in Nepal.

To identify the barriers to and enablers for the full social, economic, and political participation of women with disabilities in Nepal, through photography, an introductory photography workshop was held in Kathmandu on 25 and 26 October 2021. Local partner organizations (OPDs) including the National Indigenous Disabled Women Association Nepal (NIDWAN), Blind Women Association Nepal (BWAN), KOSHISH and the Nepal Disabled Women Association (NDWA), oversaw the selection of participants. It must be considered that all research participants are connected to one of these OPDs. Thus, information on persons with disabilities who are not associated with an OPD is limited. This limits the scope of the study and has an impact on the conclusion.

In total 10 women with different disabilities, backgrounds, age and from different parts of Nepal were invited to participate in the workshop, in which they were trained not only in technical aspects of photography but also in how to use the tool of photography as a means to express themselves. During the workshop, conducted by CBM and one of the researchers, the participants were duly informed about the objectives of the study and the research process and were assigned the task of photographing what they

perceived as enabling or disabling factors for their social, economic, and political inclusion. After the workshop, the women went back to their homes and were given three weeks to take the photographs with their mobile phones.

After the workshop, the ten women returned to Kathmandu and participated in the qualitative data collection phase of the project. Between 15 and 19 November 2021, in-depth interviews were conducted with each of these ten women based on the photographs they took. Research participants were asked to choose the four most important photos, from which they could share their stories, their experiences and their perspectives on the exclusion/inclusion dyad. In each interview, the storytelling impulse - through which the women interviewed gave an account of and reflected on the topics that were particularly important to them - was complemented by several questions from the questionnaire designed for the study. In this way, the research team was able to collect valuable data in multiple formats on the access of women with disabilities to social, economic, and political spheres. In addition, participants' accounts of their lived experiences were key to understanding the ways in which gender and disability (in addition to other relevant social categories in the Nepali context, such as caste and ethnicity) operate to create barriers to women's full social inclusion. The collected data were transcribed, translated and analysed (coded) using grounded theory (Strauss and Corbin 1996).



# **5** RESULTS

The aim of this chapter is to explain the barriers and enablers to the social, economic and political inclusion of women with disabilities in Nepal. The chapter is divided into seven parts. The first part aims to show the cross-cutting and underlying factors for the social, economic and political inclusion of women with disabilities.

In parts two to four, each sphere of inclusion is discussed separately. Parts five and six describe the role of OPDs and the role of the Nepali government. The last part of this chapter is devoted to the topic of gender-based violence. Qualitative quotes are provided to underline the findings.

#### 5.1. UNDERLYING FACTORS FOR SOCIAL, ECONOMIC AND POLITICAL INCLUSION

The available evidence indicates that women with disabilities face different barriers to participation in social, economic and political life. The data show that four main underlying factors influence the inclusion and exclusion of women with disabilities in the social, economic and political spheres: stigmatization and multiple discrimination, lack of accessibility, disability related extra costs and self-confidence. These cross-cutting issues are important as they form the base for the successful inclusion of women with disabilities.

Women with disabilities face multiple instances of discrimination and stigmatization throughout their lives, recognized at different scales: household, community and national. This multiple discrimination has a negative effect on the potential inclusion of women with disabilities in all three spheres. Disability is the main factor of discrimination, even more than other social categories such as ethnicity, caste or gender. During the interviews, the respondents clearly reported their perceptions in this regard:

#### RESEARCHER:

"What do you think is the main reason for the discrimination you faced? Was it your role as a daughter, as a person with a disability, or as a member of an indigenous community?"

#### **RESPONDENT:**

"It is my disability."

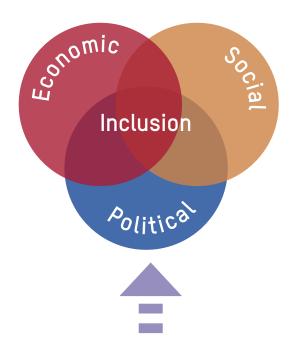
In addition, the data show that other social categories, such as belonging to an indigenous group or a certain caste, speaking a minority language and being a woman, reinforced the discrimination experienced by women with disabilities, resulting in multiple instances of discrimination. During their childhood, many of these women faced discrimination and stigmatization. The data show that girls with disabilities are often hidden in a room and lack access to basic needs (e.g., clothing) and education.

"Persons with disabilities can do anything with education and a good job."



"The slippers symbolize there are many members in the family. Dad, mom, brother, sister who are actually going outside to work. And me, I'm inside, with my disability, I was always in my room."

Insider and outsider



#### **UNDERLYING FACTORS:**

Stigmatization and multiple discrimination

Lack of accessibility

Disability related extra costs

Self-confidence

The following quote provides insight into the difficult childhood of a woman with a physical disability:

"When I was very little, I didn't even have clothes. When I went to my maternal uncle's home around the age of 8–9 years, I was naked."

This woman was sent at an early age to work in her uncle's house, which prevented her from accessing education but also from gaining self-confidence.

Access to education is hindered by both stigmatization and discrimination. When girls with disabilities attend school, their access to daily living aids and assistive devices is scarce (e.g., braille) and appropriate interventions are often not available (e.g., classes in sign language). Furthermore, accessibility in terms of infrastructure (e.g., transportation, roads and buildings) as well as quality health care and health care professionals serve as a basis for inclusion. The data show that access to health services is often not guaranteed and that appropriate medical or impairment-related treatment is often not provided, is delayed, or results in additional financial burdens.



picture no. 4
Main, I went to another hospital in ktm
at Teaching hospital where doctor tell me
that I had a heak problem and give me
this medicine Menil

"And more so we need the access to medication, and it is very difficult to just get anti-depressants without a doctor's note. So we have to come to Kathmandu all the time and that adds to the financial burden as well. So it is a major barrier."

Access to medical treatment

Most respondents had to exploit financial means to access health services and assistive devices (e.g., prostheses, wheelchairs and crutches), which puts a burden on the household's financial situation. Some interviewees argued that they need free access to impairment related treatment. Such free access would substantially alleviate the financial pressure on women with disabilities.

Furthermore, the evidence shows that women with disabilities often lack self-confidence. The discrimination, stigmatization and lack of education and accessibility leads to low self-confidence. A woman describes the lack of self-confidence as a main barrier:

"In terms of barriers, the fact that I was not confident enough to speak out loud and tell the society that this was nothing but an illness was one. I wasn't fearless then. I also couldn't work and that was tough. What added to that was my financial difficulty. It was difficult not having financial stability."

Additionally, this quote addresses the critical topic of financial stability, which will be discussed in more detail in the next section. This first part of the results chapter has shown that women with disabilities face multiple instances of discrimination and stigmatization (related to disability, ethnicity, caste and gender), disability related extra costs and a lack of accessibility and self-confidence. These factors are a prerequisite for successful social, economic and political inclusion.

#### 5.2. ECONOMIC INCLUSION

In general, the data analysis showed that all respondents are in a precarious economic situation. These women have difficulties in accessing paid employment, especially formal employment. None of the respondents are workers in the formal labour market and most of them are financially dependent on other household members. Even women with a good education could not find a paid job in the formal labour market, despite applying for multiple jobs and making great efforts. In the following quote, a woman who had access to a good education, points out:

"There have been a lot of barriers. There have been many difficulties in getting a job. For the government job, we have to take a civil servant exam called 'Lok Sewa'. A lot of persons apply for it. They do have quotas, but they don't give us the jobs. The persons have a preconceived notion that persons who are disabled will not be able to work and don't give us work. There also are barriers with the private sector. They just look at our faces and decide that we can't work. We need orientation and some guidance, and the institutions are not up for it, and the environment most of the times is not friendly."

"Because I am a woman who has a disability, I can't find many jobs. Along with that my caste as well."

#### "Where there is disability there is poverty."



Source of livelihood and social inclusion

In all economic activities but especially in access of paid (formal) labour, women with disabilities face (multiple) discrimination and stigmatization. This situation is more frequent among women from marginalized castes or women from indigenous communities. As a result, women with disabilities have to secure their livelihood in the informal labour market, mainly through their own businesses (self-employment). A woman has managed to successfully start her own manufacturing business. In this way, she has become financially independent and is able cover her household expenses, which contributes to greater self-confidence:

"After going through all those struggles (finding paid employment), I started this. Now, I don't want or need to go around looking for a job. Now I can actually give jobs to persons. So now I am independent."

The evidence shows that almost all respondents attended skill training courses (e.g., sewing) organized through the OPDs, which were meant to provide them with skill for the labour market. In the eyes of the respondents, skill training is not enough to become self-employed and financially independent in a sustainable way. In addition to skills training, they need financial support and access to information on entrepreneurship to start a business. Furthermore, the data show that the mobile phone is an enabler for the economic inclusion of women with disabilities. One business-owner marketed her product through different social media platforms. Other enablers for the economic inclusion of women with disabilities are accessible infrastructure (transportation, roads and buildings) and an encouraging and supportive family and community. Especially, social norms and power relations in households and in society influence women's economic participation.

The Coronavirus Disease 2019 (COVID-19) pandemic hit Nepal hard and had a negative impact on all respondents. They mostly reported loss of income, food insecurity and deterioration of their mental health. Different respondents describe their food insecurity as a woman in the following quote:

"We live day by day, that is, we work and earn on a daily basis. So accordingly, we bring food to the house on a daily basis, such as one or two kilos of rice. We couldn't really feed our family well. They were not yet giving out rations at that time. It was very, very tough."



Employment creation for women with disabilities

This quote illustrates the precariousness to which women with disabilities are subjected. External shocks, such as the COVID-19 pandemic and the resulting food insecurity, push them further into poverty.

This part has shown the difficulties women with disabilities encounter in sustaining their livelihoods, as well as their precarious economic situation. Enablers for a successful economic inclusion are skill training in combination with financial support, access to information, access to markets and a supportive community and environment. The following part shows more clearly the influence of economic participation on social inclusion.

#### 5.3. SOCIAL INCLUSION

"The entire community ostracized me, saying how a person like me can work. My neighbours also mistreated me and gave me stale food."

The data show that women with disabilities are often marginalized members of society due to the stigmatization and (multiple) discrimination they face. Successful economic participation is an enabler for social inclusion. Successful business owners are less stigmatized and discriminated against by society and have more social contacts. Through the exercise of their occupations, they are in contact with employees, customers and business partners and have greater success in developing friendships than women who are not economically included. Stigmatization and exclusion are prevalent from an early age and have a crucial impact on social participation. The data show that leaving the family of origin and marriage can be a turning point in the social inclusion of women with disabilities. Husbands mostly play a crucial role as key supporters and important social contacts of women with disabilities:

Furthermore, evidence shows that women with disabilities have few friendships, but in all cases they report having company and at least one person close to them (e.g., husband, friend, member of an OPD, social worker) whom they deem important. They are perceived as an enabling factor in overcoming the daily barriers that arise in the life of a person with a disability. These persons perform unpaid work. In addition, peer support groups (e.g., mental health groups) or networking events organized by the OPDs have a positive impact on the social participation of women with disabilities. A woman with a physical disability was encouraged by a person close to her, to participate in OPDs skill training, which laid the basis for her current livelihood activity:

"She encourages me to come with her, but I don't really like going out that much. So, I think I haven't had enough exposure to the outside world which is posing as a barrier now."

"I don't have any friends so to speak. I am very busy as I am at work from 7 am to 7 pm. My husband is my friend, and my customers are also my friends. But in society, if they see me, they tend to point out my wheelchair and ponder quite a lot about it. They say things like, you have a disability, how will you be able to work and other similar terms. But I don't like that"



Wheelchair at the roadside

Inaccessible infrastructure is also a barrier to participating in social activities. This prevents a woman with a disability from physically meeting her friends:

"Sometimes, I go meet them (my friends). I like to stay at home most of the time. Mostly I get in touch with them through social media. They call me to meet and relax, but I can't go there because they have stairs, and the places are at a height. So, they will also feel sad and that will make me sadder. That is why I don't really like to hangout. It is one of the barriers that prevent me from being in touch with my friends."



Lost opportunities



Now, I am very happy in my life. I have joined self Mental heath core committee as a chairperson. I am fully recover.

Peer support groups

To overcome infrastructural barriers to social inclusion, women with disabilities rely on their mobile phones to maintain their social contacts. For young persons, social media platforms are enablers for (virtual) social inclusion.

This part has shown that women with disabilities are marginalized members of society. Economic inclusion, peer support groups and mobile phones are enablers for social inclusion. The next section gives an insight into the barriers and enablers to political inclusion.

#### 5.4. POLITICAL INCLUSION

"If the persons see me and say they will do something for me, they will forget it as soon as they reach a level of power. I'm aware of the complexities of politics, but I just don't trust the political setting."

For the women interviewed, the issue of political inclusion is not central to their lives. The respondents reported that their interest in politics is very low and is linked to high distrust and low expectations of politicians

and the political system. Lack of self-confidence, communication skills, time or financial means as well as stigmatization and discrimination are barriers to the political engagement of women with disabilities. However, some of the interviewees report getting politically involved through OPDs in the field of activism or advocacy. Female politicians with disabilities act as role models and enablers for greater political inclusion of women with disabilities.

#### 5.5. ROLE OF OPDS

"The role of the OPD is really important in my life. That is where I grew up as an individual and that is where I gained the confidence that I have nowadays."

In general, OPDs play a very important role in the social, economic and political inclusion of the interviewed women with disabilities. They serve as key institutions in terms of awareness-raising and access to information - especially regarding basic rights and disability allowance. They also serve as focal points for activism, thus contributing to the political inclusion of women with disabilities. Furthermore, OPDs are spaces for networking activities, peer meetings and support groups, which are key for the social inclusion of women with disabilities. As places where skill training is facilitated, OPDs contribute to the economic inclusion of women with disabilities and provide a place for access to health care services and assistive devices. Most respondents reported positive engagement with the OPDs. However, one woman expressed some criticism of the behavior of the OPDs, indicating dissatisfaction with the atmosphere and modes of communication:

"There have been both positive and negative impacts. At first, I did not know about the policies or benefits from the government. But when I joined an OPD through CBM, I came to know of the possible benefits, where I should go and whom I should talk to about it. In the same way they made us weaker. They pass too many comments. Even if we post anything on Facebook, they would stop us and comment on why we uploaded it and all of that."

This section has shown that OPDs play a major role in the lives of the interviewed women with disabilities. On the contrary, as will be seen below, respondents expressed great discontent with the performance of the Nepali government as guarantor of their wellbeing and rights.

#### 5.6. ROLE OF THE GOVERNMENT

"I have no expectations of the government whatsoever."

In general, respondents perceive the government as playing a secondary role in their lives and emphasize that they do not expect anything from it. Their main contact with the government, governmental structures and government officials is related to the disability allowance. The data show that the disability allowance, which amounts to approximately 2000 Rupees per month, is too low to rely on for substantial aid. Furthermore, the evidence shows that not only are the rights of persons with disability sometimes unknown when it comes to obtaining the disability allowance, but also that the application process poses a serious hurdle for women with disabilities.

"I didn't know that there would be another process to get the allowance, which is a long process. My friend told me and encouraged me to begin the process. I had some reservations in the beginning, but then with my friend's encouragement, I decided to go for it. So, I took all of my photocopies and went to the municipality. I asked them if I could leave the photocopy of my documents and they could fill out the form as I couldn't do it. They agreed and said they would do it. But to this date, they haven't done it. It's been 2 or 3 years since I got the blue card, but I haven't gotten any allowance yet."

Both the application process and the infrastructure hinder women with disabilities from acquiring what they are entitled to by law, especially in the case of women with physical disabilities who are unable to obtain a monthly disability allowance or resolve business-related issues:

#### RESEARCHER:

"When you go to the ward office to collect the disability allowance, is that place wheelchair/tricycle friendly?"

#### RESPONDENT:

"It is not very accessible. I have to park my wheelchair outside and then I go in using my hands."

"They also establish them (government offices) without proper infrastructure. The tax office in Putalisadak is so far away. I have to go there with some other person to pay my taxes. And that makes me feel dependent on others."



Way to the ward office

To summarize, women with disabilities appear to rely on the government primarily for disability allowances, which are insufficient. Existing structures make it difficult for women with disabilities to know and claim their legally guaranteed rights.

#### 5.7. GENDER-BASED VIOLENCE

The topic of gender-based violence was not the focus of this research nor was it included in the research question. However, the feminist and participatory approach adopted in this research created an opportunity for respondents to suggest topics of interest to them, such as gender-based violence. Several respondents reported experiences of violence, particularly sexual violence.

The data show that women with disabilities – especially those from marginalized groups – are at high risk of violence and have no or limited access to justice. One woman with a disability framed sexual violence as a major problem in her life:

"There has been a lot of violence against women, one example being rape. I am an indigenous woman and I also have low vision. I and others alike have no access to anything, neither to education nor to justice. And it is worse for us as we are already marginalized. We have to face injustice just because of our background and the fact that we are women. I don't know whose problems are bigger than the ones that we face."



Self-defense course

Gender-based violence is prevalent throughout the lives (childhood and adulthood) of women with disabilities and at different levels (at home, in the community and in the workplace). One respondent was a victim of violence and reports that women with disabilities are forced into prostitution to cover their livelihoods:

"I do think sexual violence is at the top. I have 50–60 female friends with disabilities in Kathmandu. Out of them, only about 10 are independent and are doing work on their own. The rest of them have 2–3 men coming and going and that is how they manage expenses. They have no other option. They don't get jobs either."

In a nutshell, women with disabilities are more vulnerable to violence, especially to sexual violence.

# 6 DISCUSSION

The main purpose of this study was to provide a deeper insight into the lives of women with disabilities in Nepal and to highlight the barriers and enablers to their social, economic and political inclusion. The intersectional approach and social inclusion framework provided a suitable background for embedding the empirical findings (Crenshaw 1989; World Bank 2013). As the results presented in the study show, women with disabilities face multiple forms of discrimination and stigmatization, yet the main discriminatory factor is the disability itself. The results indicate that gender intersects with disability as well as with other social categories - such as belonging to a marginalized ethnic group (e.g., an indigenous community) or to a marginalized caste or speaking a minority or indigenous language. The stigmatization and discrimination increase with the intersection of the different social categories, are visible at all scales - household, community and national levels - and occur throughout the life of a woman with a disability. The perpetuation of discriminatory practices leads to the marginalization of women with disabilities in Nepali society.

These findings are consistent with the study of Dhungana (2006) who pointed out that stigmatization, especially against women with disabilities, is widespread in Nepal. They are also in accordance with the observations of the Committee on the Rights of Persons with Disabilities (2018) regarding multiple and intersectional discriminations of persons with disabilities. According to MacDonald et al. (2021), women with disabilities face multiple barriers to participate in social, cultural and political spaces and are more vulnerable to violence. This can be

confirmed by the data presented in this study. Furthermore, Persons with Disability Australia (2019) outlines that barriers to inclusion in different spheres are often found at the structural level (e.g., lack of access in terms of infrastructure, medical care, claiming rights) rather than at the individual level. The results of this study corroborate this assertion. Karki, Rushton, Bhattarai and De Witte (2021) and the Nepal Disabled Women Association (2019) report a gap in the implementation of existing law and policy instruments to protect and promote the rights of persons with disabilities. Data from this study show similar results. In this regard, the Committee on the Rights of Persons with Disabilities (2018) has called on the State party to take action by implementing existing legislation to prevent multiple and intersectional discriminations and protect all persons with disabilities from (sexual) violence.

# 7 CONCLUSION

Multiple discrimination and stigmatization are the main underlying factors that hinder full participation in the social, economic and political spheres and subject women with disabilities to precarious living conditions. Lack of accessibility, additional disability related extra costs and lack of self-confidence are other underlying factors that hamper the inclusion of women with disabilities. To enable the full inclusion of women with disabilities in the social, economic and political spheres, efforts must be made to eradicate stigmatization and multiple discrimination. Social awareness of stigmatizing and discriminatory practices and gender-based violence should be raised through nationwide campaigns.

The results also show that disability related extra costs, lack of accessibility – in terms of infrastructure (e.g., transportation, roads, and buildings), quality health care and trained health professionals – and lack of self-confidence are other underlying factors that influence inclusion in each sphere. These four underlying factors must be addressed to successfully achieve the social, economic and political inclusion of women with disabilities. In this sense, it is necessary to guarantee the accessibility of infrastructure, access to quality healthcare and the subsidization of disability related extra costs.

Most Nepali women and men cover their livelihoods through employment in the informal labour market, which is also the case for women with disabilities. They are pushed into self-employment due to the lack of paid employment opportunities in the formal sector. Women with disabilities face multiple difficulties to cover their livelihoods and most of them live in precarious economic situations. External shocks, such as the COVID-19 pandemic, can subject them to poverty and food insecurity. Enablers for the successful economic inclusion of women with disabilities are skill training in combination with financial support, access to information and communication and a supportive environment at all levels.

Social inclusion is tightly linked to economic inclusion. Women with disabilities who are economically successful experience less discrimination and are less stigmatized than women without a successful economic life and they also achieve better social inclusion and are more self-confident. This demonstrates that successful inclusion in one sphere can have a positive impact on inclusion in another sphere. Moreover, peer support groups, networking events organized by OPDs and mobile phones are enablers to social inclusion. Inaccessible infrastructure (transportation, roads and buildings) also constitutes a barrier to participation in social activities. Women with disabilities generally have a small circle of friends and are placed on the margins of Nepali society. These factors render women with disabilities more vulnerable to violence in general and sexual violence in particular. Further research is needed to assess the prevalence of gender-based violence. The social inclusion of women with disabilities can be enhanced by their integration into the labour market, self-confidence building, accessible infrastructure, mobile phones and OPD peer groups.

The mainstream political participation of women with disabilities is very low and is linked to a high level of distrust and low expectations of politicians and the political system. Lack of self-confidence, communication skills, time or financial means as well as stigmatization and discrimination are barriers for women with disabilities to become politically active. However, the results show that women with disabilities are politically engaged through OPDs in the areas of activism or advocacy. Female politicians with disabilities serve as role models and enablers for a higher political inclusion of women with disabilities.

Despite the existence of multiple constitutional, legislative and policy instruments at the institutional level in Nepal, which are aimed at protecting and promoting the rights of persons with disabilities, there are large implementation gaps that generate substantial barriers to the full participation of women in economic, political and social spheres, particularly for women

"I had a huge interest in studying but nobody helped me. Not even my friends. Every time I would go for help they would say 'study by yourself' at school and at home also."



Access to education

with disabilities. Additionally, existing structures make it difficult for women with disabilities to claim their rights (e.g., disability allowance). The many existing constitutional, legislative and policy instruments must be properly implemented to foster the inclusion of women with disabilities and ensure their access to basic rights and social protection.

In general, OPDs play a very important role in the social, economic and political inclusion of women with disabilities. They are key institutions in terms of awareness raising and access to information – especially regarding basic rights and disability allowance – and are sites for activism and skill training. Additionally, such organizations provide access to health care services and assistive devices. OPDs are key actors for the full inclusion of women with disabilities.

In conclusion, the results of this study show that multiple discrimination and stigmatization at all levels and throughout life are the main barriers to the social, economic and political inclusion of women with disabilities, subjecting them to precarious living conditions and placing them on the margins of society. Stigmatization and discrimination are exacerbated by the intersection of different social categories. Successful integration in one sphere can have a positive impact on integration in another sphere. Especially, integration in the economic sphere has a positive impact on the social integration and increased self-confidence of women with disabilities. The full and successful inclusion of women with disabilities in the three interconnected spheres demands urgent action to eradicate multiple discrimination and stigmatization and to improve the surrounding conditions.

# **8** RECOMMENDATIONS

The following recommendations are based on the ten qualitative in-depth interviews, which were conducted in the context of this exploratory Photovoice study. Local partner organizations of persons with disabilities oversaw the selection of research participants. Furthermore, the recommendations are in line with the CRPD.

The recommendations are targeted at different actors according to their respective roles, including the Nepali government, civil society, OPDs and development cooperation actors. They reflect the need for a 'twin-track' approach to disability inclusion by mainstreaming the concerns of women with disabilities, especially women from marginalized groups throughout all social, economic and political efforts, while also targeting their specific needs. The four recommendation areas intersect heavily and support each other.

#### ENDING STIGMATIZATION AND ADDRESSING MULTIPLE FORMS OF DISCRIMINATION

- Meaningfully consult women with disabilities and their representative organizations on all issues affecting them, in all phases of policy making and project cycle management.
- Raise awareness about discriminatory practices and existing laws and provisions in place for the protection of the rights of persons with disabilities, including social protection schemes, protection from gender-based violence and access to justice. Interventions aimed at addressing violence and discrimination must include comprehensive support and individual case follow-up.
- Establish trainings on disability inclusion, including on the rights of women with disabilities, for government officials, civil society and development cooperation actors.

- Roll-out or provide support to targeted awareness raising campaigns to combat disability stereotypes and negative attitudes and raise awareness on intersectional discrimination for the general public, including families of women with disabilities.
- Systematically collect disaggregated data on persons with disabilities (especially on sex, age, disability, ethnicity and caste) including within national surveys (e.g., census) and within development cooperation projects to track the quality and impact of interventions.
- Conduct research on the impact of gender-based violence on women with disabilities and address these concerns within existing or new gender-focused policies and programmes.

#### ESTABLISHING ACCESS TO EMPLOYMENT AND ENTREPRENEURSHIP

- Promote the employment of women with disabilities within the private and public sector.
- Train employers to apply disabilityinclusive and gender-sensitive employment practices and recognize the talent and skills of women with disabilities.
- Provide accessible, relevant and quality skill training to women with disabilities.
- Provide information, financial support (e.g., seed money), follow-up trainings (e.g., on financial literacy and savings) and linkages to markets for entrepreneurship and business development.

#### ENHANCING CONFIDENCE BUILDING AND SOCIAL INCLUSION

- Support OPDs and especially women led OPDs technically and financially:
  - to establish capacity building programs for women with disabilities, including free mentorship, exposure to decision making processes and confidence-building.
  - to connect women with disabilities to existing OPD initiatives and other initiatives on women's rights, business, politics and gender-based violence.
- Invest in support services for women with disabilities such as assistive technologies or personal assistance, to allow for equal participation in daily life.

#### ENSURING ACCESSIBILITY OF INFRASTRUCTURE AND INFORMATION

- Set-up working groups, including women with disabilities, to identify existing barriers in infrastructure and information and gradually render them accessible with definite time frames and adequate resources.
- Ensure that all new infrastructure and information in the community are fully accessible and gender-sensitive to persons with disabilities.
- Ensure accessibility of the application and distribution process for social protection benefits, including doorstep access and a meaningful amount to cover disability related extra costs experienced by women with disabilities.
- Ensure that systems have measures to provide for reasonable accommodation to women with disabilities to enable them to actively engage in social, political and economic life.

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